

**Quality Measures Workgroup:
Patient & Family Engagement Tiger Team
Draft Transcript
October 22, 2010**

Presentation

Christine Bechtel – National Partnership for Women & Families – VP

Good morning, everybody. This is Christine Bechtel with the National Partnership for Women and Families. You have joined the Quality Measures Workgroup Tiger Team on patient and family engagement. So this is a public call. We'll have time for public comments towards the end of the call. Why don't we go ahead and start with introductions in terms of the workgroup members that are on the phone? Jump in any time, guys.

Eugene Nelson – Dartmouth Medical School – Prof. of Community & Family Med

Gene Nelson, Dartmouth.

Paul Wallace – Kaiser Permanente – Medical Director

This is Paul Wallace from Kaiser Permanente.

Christine Bechtel – National Partnership for Women & Families – VP

Do we have other workgroup members on the phone? I just got an e-mail from David Lansky. He's having trouble getting on the call, so we may actually have some issues with other workgroup members also joining. We'll give David a second to get joined.

The plan for today, I don't think we're going to need the full three hours. That's good news, but the plan for today is to actually start with David Lansky leading us through a discussion of some of the methodological issues that we need to consider and provide some input to ONC for the purpose of their RFI. Then we will jump into the summary table that everybody has had a chance to look at and provide input to. We'll do a review of additions that folks have made and just to make sure that everybody is comfortable. I know you all have that in your e-mail. Allen sent it yesterday.

Then what I've done on my version of that table is I've also added a column that says key questions for the RFI or RFP, so that as we go through some of our domains or our sub-domains, rather, that we can flag some key issues that we want to suggest that ONC explore specifically in the RFI. And then we'll take some public comments as well.

I'll back up and say that we did present— Is David on the phone yet?

David Lansky – Pacific Business Group on Health – President & CEO

Yes, I'm here.

Christine Bechtel – National Partnership for Women & Families – VP

Great. David, I don't know if you want to let folks know about the Policy Committee, the presentation you made, and the hearing next week.

David Lansky – Pacific Business Group on Health – President & CEO

What the Policy Committee and the staff wanted to do this week was to present the work we've done in clarifying the domains and giving them definition, and in developing sub-domains and giving them definition, and then introduce the measure concepts, although I will say that the full committee didn't have bandwidth to get into the measure concept level. At this point what we asked them to do was essentially

affirm that we've got it about right on the domains and sub-domains, and they got to eyeball the measure concepts. Presumably they can give us any feedback they wish.

I'll just, in addition, say they did not want to look at individual measures at this point. I think ONC itself is not ready to look at individual measures, although they saw all the tiger team's ability to list the measures as a useful thing, just to put some substance and examples around the concepts we've been talking about. But, at the same time, they don't want to presume that we've already gotten to the point of tagging measures to concepts. I think one of the reasons for that is—and particularly Dr. Blumenthal's recognition that we are one of five of these tiger teams on content. As you look at even this table that we got from Allen, we've already got whatever, 15, 20 potential measures down here. That's by far a greater scope than what they envisioned being able to propagate for stage two meaningful use in terms of additional clinical quality measures.

Our challenge of the whole process going forward will be to start looking for parsimony and elegant, crosscutting measures, which tap multiple dimensions that we and the other tiger teams have been raising. In some sense, what we've done is lay out a fairly broad landscape with a lot of content and ideas in it. Soon the challenge will be how to compress this back into a more manageable scope. Therefore, we don't want to get into getting behind individual measures for every single concept knowing that the next task is actually going to be more of a reductionism task.

That said, the process going forward, and I will say the Policy Committee did endorse the identification of sub-domains that we did. They give us encouragement to go forward. The next step will be next week. On the 28th, there will be a hearing or a meeting of the full Quality Measures Workgroup. At that time, there will be several public witnesses will come in and comment on the state of development of these measures and sub-domains—sorry—the measure concepts and sub-domains so far.

Out of that hearing, the next stage will be the development, and each of the tiger teams, including ours, will present to the full workgroup the domains, sub-domains, and concepts that we've developed to this point. So probably our key task for us today is to feel like we've gotten as far as we're able to go on getting the measure concepts articulated for purposes of bringing them to the full workgroup. Hopefully the full workgroup will be happy with what we've done to date, and that will then be transmitted to ONC for purposes of developing the request for information or request for comment, which will go out in mid-November. I guess staff will have a couple weeks to translate the work that we've done into something for public comment.

One thing we've just started talking about with the staff is, as they look at the five major domains, of which ours is one, can they take all of the measure concepts from all of the five tiger teams and crunch them into a more concise set of topics. For example, some of our sub-domains repeat in other tiger teams' areas. Hopefully they can do an analysis of all the content that's been raised by groups like ours and bring it down to a more coherent and fewer number of topics for public comment.

That's the work going forward. Does that Christine summarize where we are? Anything else you want to add to that?

Christine Bechtel – National Partnership for Women & Families – VP

No, I think that sounds great. I want to give the workgroup members a chance to ask questions, but I think that for our purposes today, David, it makes the most sense to have the methodological discussion. But then after that, rather than going back through the potential measures column, it probably makes more sense to focus on making sure we have some solid thinking around how measures and measure concepts can be HIT enabled or HIT sensitive and then flagging any questions that we think are really important to explore for the RFI. Does that sound right?

David Lansky – Pacific Business Group on Health – President & CEO

Yes, I think so.

Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO

Can I add a little something? Sorry I was a couple minutes late, and I will have to jump off at 8:00, but one of the things in looking at the measures or the concepts that were presented to the full committee, that our end goal is— We all realize that our end goal is more outcomes oriented. The comment was made that a lot of the measure concepts that were proposed still seem to focus a fair amount on structure and process. It turns out, I think that our particular tiger team's work is potentially more relevant to the outcomes side. Some of the ways that we're hoping to get at it maybe also be certainly HIT enabled if not sensitive. I think there may be extra room for crosscutting measures coming out of this workgroup just because it tends to be more outcomes focused.

Christine Bechtel – National Partnership for Women & Families – VP

That's a great point, Paul. Thank you.

David Lansky – Pacific Business Group on Health – President & CEO

Paul, let me just add to that too. That's a really important point that came up at that meeting. The other implication to our methods discussion we're about to start is that there may be a number of measures that are most effectively captured from patients, even though they are not the patient engagement measures. Our platform, so to speak, for data capture might be valued by the other parts of this process as well.

Christine Bechtel – National Partnership for Women & Families – VP

Any questions for David or Paul? Did we have any other workgroup members join the call?

Dana Safran – Tufts University – Director of the Health Institute

Yes, Dana Safran.

Eva Powell – National Partnership for Women & Families – Director IT

This is Eva Powell. I was on, but at the printer.

Christine Bechtel – National Partnership for Women & Families – VP

Anybody else? Terrific. David, do you want to lead us through the methodologic discussion?

David Lansky – Pacific Business Group on Health – President & CEO

Yes. Did everybody get a copy of the memo I sent out last night with some notes on methods or anybody not have it that we can still shoot it to? I'm sure people

Eva Powell – National Partnership for Women & Families – Director IT

I don't have it. If you could send it, David, thanks.

Christine Bechtel – National Partnership for Women & Families – VP

I'll send it to you, Eva. I've got you.

David Lansky – Pacific Business Group on Health – President & CEO

This is obviously a starting point, and I appreciate it. Gene, and I had a brief conversation and he sent some notes, which I tried to capture here, but there's a lot more depth behind the thoughts that he started raising. What I tried to do was just being to lay out what at least is in my head as some of the methodology issues that we need to speak to. I'm sure I did not get, by any means, all of them or even the right ones.

Let me just start going through this, and I think all we can probably do today is say, are these some of the right issues? Are there other issues that are not reflected here? Are some of these no-brainers that we should just answer now and move on, or do we need to have a process in the next period of time to really work through some of these? Let's just do kind of a high level gloss on this today.

The premise in my little background section here is that there is going to be some data we want to capture from patients or perhaps from devices or other mechanisms in the patient's home, or at least remote to eligible professional or hospital. For the purposes of this discussion, I was focusing only on subjective information coming from the patient rather than monitoring or other types of data supply, which we may want to come back to as a methodology question. But for the moment, let's just talk about the patient reported information.

I did leave both hospitals and eligible professionals in the same discussion for now, although it may be wise to separate them for a lot of reasons. But for the moment, I kind of clumped them together. Gene's note, you see in the middle of the first page, was just to really challenge us to think in two pathways. One is essentially the survey approach, and particularly he was mentioning the health of senior survey, which is essentially a panel study in which a population is studied over time.

Secondly, he suggested that we give some thought to really the flow of patient information into the care process itself, which is, as he called it, design in, which is a really attractive scenario, especially for HIT enablement. I think we should certainly come back to that discussion as well. But in this note, I didn't try to address it.

Let me see if Gene is on the call today. Gene, are you on?

Eugene Nelson – Dartmouth Medical School – Prof. of Community & Family Med

Yes, I am.

David Lansky – Pacific Business Group on Health – President & CEO

Do you want to add any more about this sort of pathways decision, fork in the road that we should talk about.

Eugene Nelson – Dartmouth Medical School – Prof. of Community & Family Med

I think you've laid it out well, and it could be approach A, one, or approach two or, in some senses, a hybrid. As we explore approach two, I think there's a hybrid that brings in the periodic survey as part of, for example, periodic full health assessments, as done in health systems.

Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO

David, if I could just add, I, like you, really find number two pretty attractive, not only because it can leverage the HIT and bring information into the decision error assessment, but I like the ability to bring it into decision making. So if we as healthcare professionals got information about whatever it is, either observation as part of the treatment plan, or meds or procedures that are done, it would be fabulous to know are they working, and are we getting maximum benefit? Do we add more to something? Does that produce any more compared to the cost ... side effects, complications of doing something? The idea of being able to do more than just survey in a more retrospective way is very attractive to me.

Christine Bechtel – National Partnership for Women & Families – VP

I agree with that. I think, if you think about patient preferences and values that incorporating those into the care flow is really critical. I think you also need an assessment of sort of how it went, and that will feed part of how it's going, and that's the survey approach. So I like both approaches.

Let me just say two things for people to think about. One is, I've been thinking a lot about how we might take any kind of survey data, whether it's CAPS or another experience survey or how is your health survey, and feed that back into decision support modules for the clinician. I think that's way far out, but I think it might be an interesting idea to explore in the RFI the feasibility of doing that. That's the first thing.

The second thing is a question that I have, which is for pathway number one. That involves an independent entity like CMS administering the survey longitudinally across a sample population, but is

that necessarily specific to a provider? I want to make sure I'm understanding the ... senior survey administration.

Eugene Nelson – Dartmouth Medical School – Prof. of Community & Family Med

The health of senior survey administration has been going on since 1998. In effect, Medicare advantage programs have taken a sample of 1,200 patients in the spring of the year, and the survey is sent out in a standard way. Then two years later, that same survey is re-administered to that same group, to the respondents of the first survey. So it's 1998, followup two years later, and then to 2010, a followup on 1,200 people two years later.

Christine Bechtel – National Partnership for Women & Families – VP

For the meaningful use context though where these measures are tied to evaluating whether an individual, either clinician or a hospital is a meaningful user, have we or are we—? Can we contemplate a model that doesn't have a third party administering it? It has the data actually coming back to the physician so that it's administered, or the hospital, so it's administered through a PHR or a portal or an e-mail, which is what the ABIM module on maintenance and certification for patient experience, they have an e-mail.

Eugene Nelson – Dartmouth Medical School – Prof. of Community & Family Med

Absolutely. That's what I was, when I just mentioned earlier that it's possible to think of an approach like one being embedded in a design and approach like two. For example, at Group Health Cooperative, they have a very nicely, well rounded health assessment that is completed essentially whenever a primary care patient receives their periodic health exam. If it's a young person, age 25, it might be every five years. If it's an older person, age 68 with a couple of chronic problems, it would be administered annually. That is part of their Epic based portal and electronic health record system. It's fed forward into the periodic health exam.

We do the same thing at Dartmouth. We go out to our Web portal, and we invite the patient, be they primary care or specialty care, to complete a health survey, and then that's fed forward. So at the point of service, the clinician or the clinical team and the patient, are on the same page with respect to that patient's current and changing health state or health status.

Christine Bechtel – National Partnership for Women & Families – VP

That's the most appealing to me. I don't know about others.

Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO

I wonder if I can sort of suggest maybe a model of how to think about this, and the analogy I'm thinking about is quizzes and final exam. Quizzes are, are you getting it kinds of assessments, and the final exam is, have you put it all together. I'm looking at this hybrid of one and two. The quiz is, are you getting it? That's both an internal assessment for the individual student, but also an assessment by the faculty of, am I effectively communicating this information? Then the whole class, we should figure out how the professor and the student is doing by the final exam. It's not just an assessment of the "students".

If we take that into our situation, we'd love to be able to figure out, am I doing the right thing, me as a healthcare provider or a professional, with the patients and vice versa. Then from, let's say, an ACO kind of assessment, that would be the final exam. How are you doing with your population, healthcare organization? So I'll just stop there, but it's sort of a way of saying these are not two different things. These are assessments of each individual party and the diet. How are they doing?

Christine Bechtel – National Partnership for Women & Families – VP

Paul, if I'm understanding what you're saying, I think it makes a lot of sense so that you might think about having a meaningful use objective that says the ability to survey, and they can choose. Do they do a patient experience survey? Do they do a how is your health survey, a functional status survey? But they need to be doing something around patient and family engagement on a more ongoing basis, and then

that's the quiz piece. Then later there is, are you putting it all together through an independent maybe administration of like a patient experience survey. Is that what you're thinking?

Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO

Sort of, only surveys to me seem to be a little bit loaded, and usually it feels retrospective. How did you do over the past 12 months or whatever duration? The ongoing sort of feedback into the ... of care is more of incorporating patient information rather than an assessment or retrospective final exam. It's like ... but I'm just trying to give a different flavor. Instead of using the word survey, it's almost like an ongoing – you continually incorporate the patients. It could be lots of things: patient data like pain scores or mental health scores, or it can be their experience and their understanding and the ... attitude I believe that Judy Hibbard talked about. There are lots of things you could be, lots of information you can use about the patient that can help you make ongoing tweaks to your care plan, so to speak.

Paul Wallace – Kaiser Permanente – Medical Director

I like Paul's metaphor about the quiz and the final exam, but I think there's another level to that too that a great deal of information the clinician's use really comes more through ... the metaphor, to be a conversation, even without a quiz or the accountability around that. One of the challenges that we've had with, for instance, using HRA data, is that clinicians tend to rely more on the dialog, the running dialog with the patient than a formalized instrument like an HRA.

We're seeing that that conversation is changing dramatically through using things like secure e-messaging. But the ability to impose the structure of the survey and pull the data out is something that clinicians push back on a fair amount. I think one of the challenges here is how to standardize and structure the exchange while respecting the clinician's workflow because there's nothing they're more strongly attached to than their workflow.

Eva Powell – National Partnership for Women & Families – Director IT

Yes.

David Lansky – Pacific Business Group on Health – President & CEO

Going back to Paul Tang's earlier point, we have to think about this with two lenses. One is clinical quality measurement, and the other is outcomes. To your last point, Paul Wallace, it's interesting to think about what is the outcome of interest that reflects physician/patient communication and engagement around these domains that are the sort of artifact of the quizzes, or the quizzes are the artifact of the exchange. Is there a quality measure there that we could get out? Maybe it's already reflected in the discussions we've had about patient activation and so on. Or maybe it's a provider side measure of whether the provider is well-informed ... current about the patient's health status by means of whatever technology, whether it's a conversation, an e-mail, or a quiz.

Eugene Nelson – Dartmouth Medical School – Prof. of Community & Family Med

I'm extremely sensitive and tuned into what Paul Wallace just said about pushback. People, clinicians have practiced in a certain way. So if you disturb that practice pattern with a new set of information that is not valued and understood, it will tend to be resisted. Then if you go back to our logic models and short term outcomes, improved measured health outcomes for patients using a certified EHR, etc. This patient reported information is transformational, and that does mean change and changing, and so there will be resistance. Yet, if this patient reported information that only the patient can report on, such as their functioning status and their pain level and their health behaviors and their level of activation. If that is not on the clinician's radar screen when the clinician or the clinical team are looking at the current regimen with the patient, making decisions about the next regimen, and to evaluate how that regimen is working for the patient, or how that care plan is working for the patient absent these measures, you're a bit lost.

A person like Jim Weinstein, a doctor who has used these feed forward systems for over a decade, or a Stefan Lindblad, they say they can't be a good doctor without the information. It's like practicing without my diagnostic tests and my MRIs. I don't have the information that I need on how the patient is doing

absent having these feeds in. They're new feeds, and they aren't necessarily all is embraced and appreciated if they come in over the transom. So the resistance and misunderstanding is very easy to evoke.

Eva Powell – National Partnership for Women & Families – Director IT

I just wanted to interject that I pulled up the survey, and much of this information is already being collected as a part of assessments, but not necessarily by physicians. Much of this information is collected routinely by physical therapists, social workers, other disciplines on the team. The problem is that, A, it's not all being collected as part of the same instrument. B; it's usually collected on a paper, obviously in a paper chart, but also somewhere that is not usually where a physician might look for it, whether it's in a pros PT note in the back of the chart or what have you.

So, I think the value to this is that it's bringing together information already being collected in many instances, and so yes, I think the point about physician resistance is important and that this will require change to workflow. But I don't know that that change is necessarily as dramatic as we might be thinking about it in the sense that, at least in my experience, physicians routinely call on physical therapists, but at the last minute when they're ready for the patient to go out the door, and they've suddenly figured out that that patient can't walk, but five steps. They were planning on that person going home. So then the physical therapist is called in last minute. Everybody is in a rush.

I think the value to this and maybe the way to talk about this is an assessment, which does bring it into, I think, the present time. But then also to talk about it in a way that the information comes from the patient, but isn't necessarily collected by a physician. Then the change in the workflow comes in that the information is available at the very beginning of the person's admission or at the beginning of the person's visit to an office.

Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO

Let me try to—

Dana Safran – Tufts University – Director of the Health Institute

I don't—

Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO

Sorry.

Dana Safran – Tufts University – Director of the Health Institute

Sorry. I was just going to say, I don't think you want to underestimate just how transformational this would be in the visit though. What you're saying that the data already being collected in various places is encouraging, but getting that data into the flow of care and, I think, as importantly as several folks have already emphasized, getting clinicians to view it as the tool they can't live without, pieces of information they can't live without in order to take good care of their patients is so far from where we are for most physicians today that we really have to take that in.

Eva Powell – National Partnership for Women & Families – Director IT

Yes, and I wasn't intending to diminish that. I'm just saying that perhaps it's good to remember that this information that's already, in many instances, already collected, and is already used. It's just not used in the way that's most efficient and effective. So that's sometimes helpful in helping people make those transformational changes to understand that this is the same information they've been using. It's just if they can make changes to their workflow, this actually will end up being easier for them, to recognize some similarity to what they're already doing.

David Lansky – Pacific Business Group on Health – President & CEO

Let me pull us back to today's charge, which is, this is a good discussion, and there's a lot of potential here. It seems to me maybe Paul Tang should also consider whether some of this flows back into the

meaningful use functional requirements, which we haven't really had this conversation in that arm of our discussions more broadly about meaningful use. But it obviously fits potentially into what the patient engagement functional requirements would entail, and also care coordination, as Eva was saying.

For our purposes now, which are really how do we collect data from patients for clinical quality measurement and knowing that, with the pressure for parsimony, we are going to have to provide a methodology approach, which addresses some of the less exciting domains like CAPS and other platforms, measurement platforms. Can we bring our conversation back around? There are some lessons distilled from this exploration of the rich feedback model that we've heard about from Group Health, Dartmouth, and elsewhere that informs how we want to think about the methodology platform for clinical quality measurement.

Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO

I wonder if there is something we can draw from this? One is that there was a concern about pushback and other unfunded Band-Aids to collect data, and Eva pointed out some of this is already there, but it's not presented. That actually is a software problem. But to get back to something we also discussed at the Policy Committee, which is, we want to be less and less prescriptive. So we sort of started out with a lot of structure and process in stage one, but certainly by stage three, we want to be much more, did you get the job done? I don't care how you did it.

David Lansky – Pacific Business Group on Health – President & CEO

Right.

Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO

Similarly, in this discussion, rather than say you need to use survey X, and it has to be done monthly or quarterly, which is so prescriptive, could we say something like regularly incorporate patient generated data or experience? In other words, something that you use the feed for concept without prescribing how it is that you do that. Now, for a separate exercise for the reader, how do we assess that, but it just allows for more innovation and allows people to figure out how to get this information, incorporate it, and start that cultural change without being oppressive.

Christine Bechtel – National Partnership for Women & Families – VP

I understand where you're going, and I don't disagree with the sort of conceptual approach. Where I think I get a little nervous is, it is possible to get to better or different health outcomes without doing meaningful engagement and partnership with the patient. If we think about what we know patients are concerned about in an IT context, it's going to impact my relationship with my doctor. It's just going to become cookbook medicine. These are some of the things that the doctors are concerned about too.

I think there is a balancing of outcomes and, at the same time, one of the outcomes has to be care that is respectful of patient preferences, however you go about doing that, whether you're using an experience survey or an activation survey or shared decision-making measures or whatever. The idea of regularly incorporating patient generated data I like if we can state the goals because I don't think it should be as simple as, you're just getting daily blood pressure readings. This domain is about patient and family engagement and not just patient generated data. So if we could articulate the goal that incorporating patient generated data is designed to achieve, then I think we're closer.

Eugene Nelson – Dartmouth Medical School – Prof. of Community & Family Med

Christine, to that point, we were having this conversation this morning about the Dartmouth experience and using the patient reported outcome, feed forward approaches in now about 17 different clinical populations. And when you step back and say, why is it being done, the bottom line, one of the bottom lines is the reason to feed forward the patient's report on their health status that are needed for health assessment, and the reason to formally design shared decision-making into the flow of care is to engage the patient. That's a primary goal. Two of strongest mechanisms that we found to engage patients meaningfully is to let them say how they're doing in their health in ways that are meaningful to them, and

to make sure that they're engaged and informed in a shared decision-making environment, so that's a primary goal.

A second primary goal, not the same as patient engagement, but to the point of healthcare is that in order to improve health outcomes, we have to track them. We have to track the outcomes as they evolve. We have to build that outcome tracking into the flow of care. So, for the purposes of engaging patients, health state information and shared decision-making engagements are critical. Then, to make care better, and to be accountable for the care we provide, we have to track outcomes. You get a two-for by using the feed forward patient reported information.

Christine Bechtel – National Partnership for Women & Families – VP

Part of what you're saying is just the act of a patient uploading their blood pressure readings is a direct demonstration of their engagement in care. I think that's right. What I think I missed though is you believe—God bless Dartmouth, Kaiser, and others—that you've got to have health status. You've got to catalog patient preferences. That's critical. But we don't see that happening in most of the practices out there today. So I'm trying to balance Paul's suggestion that we not get overly prescriptive and allow for innovation to happen by just having something that says some kind of a measure of whether there's regularly incorporated patient data.

Eugene Nelson – Dartmouth Medical School – Prof. of Community & Family Med

Yes. One of the things that it's very much in my assumption structure, but it may not be correct, and it might not be shared, is that one point of the meaningful use will be public reporting of critical outcome information that is a byproduct of the care, flow, and the patient's care experience.

Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO

Christine, we were just talking about "quizzes" that did not obviate the need for a final exam, which asks questions like did your physician involve, include, incorporate your preferences in making decisions and notions about shared decision-making. So if the only thing they did was upload their sugars or their blood pressures, you probably wouldn't score very well in the final. But trying not to be prescriptive in the ongoing assessment and incorporation of data in the decision-making, I think was the point I was trying to make.

Christine Bechtel – National Partnership for Women & Families – VP

Okay.

David Lansky – Pacific Business Group on Health – President & CEO

Yes. I'm still trying to be the process police here. I think our task here is, I mean, it sounds like a lot of the things we're talking about now, back to the final exam, we're focused on the final exam at this point in this committee. Whether what methods we use to capture data for the final exam, there's a lot of—and to your point, Paul—it seems like if we've done our job right on the quality measures for patient engagement that are on this page that Allen sent out today, then a lot of these methodologies for improving patient/provider communication and engagement about which we want to be agnostic, at the quality measurement point of view anyway, we want to say, whatever, whether it's an in-person conversation or an e-mail or a fax or an online interaction, quizzes, we don't prescribe what the right uniform toolkit is to achieve better patient engagement and shared decision-making, and all the other things we're looking at. We just want to administer the exam at the end of the cycle or mid cycle to find out if you're succeeding with that goal.

The other subcommittee, the Meaningful Use Workgroup does want to develop functional criteria that assess whether the meaningful user is implementing functions using HIT that will support the achievement of these outcomes. As you said, we want to balance whether we focus the lens more brightly on the process, on the functions, or more brightly on the outcomes depending on which stage we're at. So I'd kind of like to parse this discussion to those two branches and push some of this

operationalization stuff into the Meaningful Use Workgroup, and keep only the final exam discussion in our workgroup.

Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO

I think that makes a lot of sense, David. That's a good way of presenting.

Paul Wallace – Kaiser Permanente – Medical Director

David, I just had a question though because I think, as we've talked about how we want the measures to ultimately reflect health outcomes, I think where I'm worried is that I think there could be a disconnect here in that a lot of the issues around patient generated data aren't even to the structure phase yet. There's sort of like a first order question of does the capability for this information to be collected even exist. This first level is sort of, is it enabled? The second level is, does anybody pay attention? Then the third level is, did it make any difference? But I think we're way back at the sort of, does this capability even exist level.

David Lansky – Pacific Business Group on Health – President & CEO

I think we have to keep ourselves accountable in the sense that any clinical quality measure we recommend as a national requirement, so to speak, has an evidence base behind the validity of doing so, to your last point, Paul, that we actually have evidence that using this particular approach and this particular dataset leads to a clinical quality impact of some kind. There maybe, obviously, sporadic data here and there, but we will, at some point, be held to a pretty high standard by the Policy Committee and by CMS. So we should feel good about that evidence base, as we go into the next round of, at least the exploration, through the RFI.

Given our time on this topic is going to run out soon, let's go back to the methods paper and, again, see what lessons we want to draw from this aspiration that we've all endorsed to take pathway number two and flush it out. Again, leaving aside whether we have— We could talk about which of the clinical quality measures we've already endorsed as a workgroup, as a tiger team. Not measures, measure concepts. Capture the enhancement to patient care that is enabled by pathway number two, and then maybe we'll, through Paul, recommend that the Meaningful Use Workgroup consider this approach as part of its thinking, which in turn may end up being handed off to the certification and standards process. But, for the moment, there's a round of thinking to be done, I think, by the meaningful use committee as to whether this is a piece of what meaningful use really means.

For our purposes today, especially at least with this memo that we started looking at, I wonder, Christine. Can we kind of hold this conversation and move on to some of the other issues and just at least do a quick pass through them on the more traditional survey front?

Christine Bechtel – National Partnership for Women & Families – VP

Sure.

David Lansky – Pacific Business Group on Health – President & CEO

I know this is not nearly as exciting, but I think we are being asked to respond to the questions that at least I started listing here. I would appreciate a quick set of gut-check answers to some of these questions in case any of them are easy. The rest of the memo, after this broad pathways discussion that we just explored, says let's assume we're just doing a plain old survey, a CAPS type survey, cross-sectional survey that has a bunch of items in it, which produce some scales that are reportable for quality measurement. Maybe the mental model I had was something like CAPs or the patient activation measure, something pretty well established. There may be a different flavor for hospitals than there is for eligible professions. We'll just postulate that.

Then the series of five or six questions I had, I think, are some of the methodology problems, so let me just tick off the ones I enumerated, and maybe we can add or remove some from the list without trying to answer them. The first one was timing of administration. Is this done as a single annual cross-sectional

sample that just on every November 3rd, it's just done? Or is it tied to a specific visit or admission? It's a post-visit survey or a post-discharge survey, for example, and there's a mechanism for tying it to an activity.

Or is it some trend data with a pre/post administration, a little bit as the health of seniors project that Gene described earlier. You could do either beginning and end of year for some general population, or you could do it pre/post knee replacement, pre/post anginal workup, whatever. There's a set of issues around when the survey would be captured. Any general reaction to that topic as an appropriate topic for us to address?

Dana Safran – Tufts University – Director of the Health Institute

I do feel it's an appropriate topic to address. I guess what I'd say is that we may need different methodology for different populations. I know that's a messy answer, but in terms of the functional health outcomes, I think when you were just pointing to again in terms of ... populations that have had a particular condition, then maybe even a particular intervention where we're going to be looking for change over time and going to need that longitudinal view, meaning longitudinal view on the same patients. Does that, in terms of overall assessments of how ... on patient engagement that I think we can look at cross-sectional measurements, that is the population itself doesn't have to do surveys more than once.

I think that surveys that happen just once a year with reference to the past 12 months are a starting point that can work fairly well just for getting clinicians used to the experience of receiving patient experience data, but that at the moment anybody actually wants to engage with that data and do something about their care. They really want the data to be more current, and they want it to be more focused on particular visits and what happens. So then the last ... I would just point to is the limitation of those is that it's, at least as far as my experience goes, it makes it very difficult if you've got a visit focus to ask about experiences that, you know, went through the integration aspects of care. That's the challenge is that in some ways we need that kind of last 12 months too in order to capture some things that we want to capture that the system missed that aren't just what happens inside the box of the office visit or the encounter. Clearly just a few thoughts to get us started.

David Lansky – Pacific Business Group on Health – President & CEO

That's good. That's very helpful. It sounds like there's some complexity to how we end up answering this question.

Christine Bechtel – National Partnership for Women & Families – VP

Dana, can you go back on mute? Good. She just did. David, can you just summarize what you heard Dana say a little bit because it was hard.

David Lansky – Pacific Business Group on Health – President & CEO

I heard there are advantages and disadvantages of each of these three approaches that I laid out, and without recapping everything Dana said, what I took away from that is we will need to be sharper about which objective we have with the data resulting from the relevant set of quality measures that are deployed on this platform.

It seems to me there's kind of a grid emerging from what Dana said, which is, looking at the measures that ultimately emerge from the process. Let's say a patient activation measure or a continuity of care measure or a functional status measure that needs to be captured from the patient. What content, what measure we want to capture may correspond to a different timing strategy, and we can't answer that in the next five minutes, but we'll have to come back to it with that thought in mind. Does anybody agree or disagree with that general implication of Dana's comment?

Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO

I think the more relevant the measure the better, so I guess I would speak more towards B and C over A. Let's put it that way, I guess.

Christine Bechtel – National Partnership for Women & Families – VP

I think it's tough for me. I think I'm saying something similar or maybe the same as what Dana is saying, which is, if you're talking about a patient experience survey, then there's a lot of debate about do you do it once a year, or do you do it after a visit. When is it most helpful to the provider to get that feedback, etc.? But if you're talking about a measure that is not experiential that is more a health outcomes piece, then C starts to look a lot better. Do you know what I'm saying? I think it depends on what the quality measure is we're trying to get at, as to the timing.

David Lansky – Pacific Business Group on Health – President & CEO

Let's hold the thought on this one and move on to try to make sure we get our list of issues understood before we have to wrap up this part of our call. On the mode of administration, I just listed the obvious candidates that we use now to collect surveys, and I raise the question, is it a safe assumption for this discussion that we're only going to propose data collection that uses either Web or e-mail, some electronic medium rather than phone, mail, or other. Does anybody think we should keep on the table the idea of doing a non-e-enabled data collection methodology?

Eugene Nelson – Dartmouth Medical School – Prof. of Community & Family Med

I think, for the most part, that's right. It is possible for IVR, interactive voice response, to be conversational and to be automatically encoded using voice, Dragon-like software, and having a rather high degree of reproducibility. But I think, in the main, that's correct.

Christine Bechtel – National Partnership for Women & Families – VP

Yes, David. I struggle with this question because that is the overall context for what we're talking about here, which is meaningful use of health IT, and so on that account. But on the other hand, we've also said in Policy Committee that everything is sort of per patient preference, so as I think about collecting health status or activation or experience information from older people who have multiple chronic conditions, these are the high users at the highest cost and one of the most important populations to get to. Web and e-mail may not be great, and so we don't want to limit access. But on the other hand, the context is health IT. So I struggle a little bit on this one.

David Lansky – Pacific Business Group on Health – President & CEO

I'm partly making the recommendation because I don't think anyone will allow us to commit the cost that's required to capture data, especially from those difficult to reach populations.

Christine Bechtel – National Partnership for Women & Families – VP

Right.

David Lansky – Pacific Business Group on Health – President & CEO

Even though it may be methodologically and intellectually right, I don't think it's going to happen.

Christine Bechtel – National Partnership for Women & Families – VP

Yes, I hear you. I agree.

David Lansky – Pacific Business Group on Health – President & CEO

Let's take the note, Gene mentioned about IVR as another methodology to consider. Your suggestion, Christine, that we be very sensitive to the vulnerable populations, and you broadly described as a factor here and the kind of case mix problem.

Christine Bechtel – National Partnership for Women & Families – VP

Right, and recognizing the reality of that, again, is a real challenge.

David Lansky – Pacific Business Group on Health – President & CEO

Survey administration

Dana Safran – Tufts University – Director of the Health Institute

One thought about that, David, is that while I don't ordinarily think it's a good idea for surveys or patient data collection to happen in the practice setting, particularly if it's going to be an evaluation in any way of the care that they're receiving. Some of the functional health outcomes and some of the other things that you might want to ask about for hard to reach populations, I'm imagining maybe they could do in the context of the setting where they do have handheld or some other technology that's available to them there.

David Lansky – Pacific Business Group on Health – President & CEO

Right.

Christine Bechtel – National Partnership for Women & Families – VP

That's a great point.

David Lansky – Pacific Business Group on Health – President & CEO

Yes. Christine, let me just do a time check with you. I know we're going to lose both me and Gene at 11:00, which is in a few minutes.

Christine Bechtel – National Partnership for Women & Families – VP

Paul.

David Lansky – Pacific Business Group on Health – President & CEO

Me and Paul Tang, I think.

Christine Bechtel – National Partnership for Women & Families – VP

Yes.

Dana Safran – Tufts University – Director of the Health Institute

And Dana.

David Lansky – Pacific Business Group on Health – President & CEO

Christine, why don't I, as soon as I know the next four or five issues are all meaty, why don't we consider how best to— I don't know that we have to have answers to these questions. Let me just ask sort of a high level question. Those of you who have read through the rest of the issues here, are there some that you think are just irrelevant, we don't need to talk about as a committee going forward? Are there some big issues that are just missed that we need to add to this list?

Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO

I have a question on sort of who administers the survey and how it's administered. I don't really know the answer how to resolve this, but I've observed a couple things. Remember Neil's comment at the HIT Policy ... well, it's nice that we have a set of visions and a set of objectives, but actually all of the, whether it's providers or hospitals, have some things that they have to contend with locally as well. In other words, we can't ... all of their time.

One thing comes to mind, and I've participated in both the hospital setting and the outpatient setting are these third party administered patient satisfaction surveys. One of the issues is patients who return surveys rate their healthcare provider organizations high. What happens is they all are at the 90% or between whatever, 88% and 94%. So the percent tile then becomes widely differing, even for a small amount of absolute percent difference in the survey results.

The consequence is that you may be 2% down compared to your neighbor, but you're 40% tile point different. That causes a lot of use of resources to chase maybe a marginal cost. It's almost like comparative effectiveness research. So my concern is, some of the things may not be measuring the

contemporary things like patient sat versus the experience of care. The other is if it's topped out, in a sense, and you've basically made percentile differences out of very small true differences and caused the organization to divert resources from other things like assessing patient preferences, you could have an unintended, but predictable, negative consequence. That seems like the big issue, and I don't know how to—but it also seems relevant to this group's activities.

Eugene Nelson – Dartmouth Medical School – Prof. of Community & Family Med

What you're saying is very true. I've seen it over and over again. It might fit under the measure of computation issue. When you have a measure that has ceiling effects, it's not a good measure to begin with. Then when you use percentiles, you compound it.

Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO

Exactly. It's been very destructive, actually, I've seen.

David Lansky – Pacific Business Group on Health – President & CEO

Christine, I'm just going to switch phones for a minute, so if you can keep the conversation, I'll be right back.

Christine Bechtel – National Partnership for Women & Families – VP

Okay.

Dana Safran – Tufts University – Director of the Health Institute

I was just ... that's such an important that just got made, and the other thing that's going to affect how ... the scores are is when the survey is administered relative to when care was received. So we know that to do it on that day ... we have to do it on that day in that setting. You have much worse ceiling effects than if you do it a week later and outside of the setting, so those timing issues are really key to the points that were just raised.

Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO

I think what we're saying, and I'm glad to hear other feedback, is that from a methodologic point of view, and I'm sorry David's off for this moment, this might be a very major thing having a huge impact on resources and the eventual output or good that this program does.

Josh Seidman – ONC

It just might also be valuable to think about specific recommendations reflect the experience with different kinds of instruments and even different constructs may have different ceiling effects.

Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO

Yes.

Josh Seidman – ONC

Gene and Dana, you might want to sort of provide some direction as to whether there are certain constructs that are more susceptible to ceiling effects.

Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO

Dana certainly mentioned timing as a part of a construct really that's important.

Eugene Nelson – Dartmouth Medical School – Prof. of Community & Family Med

This is a bit technical, but if you use really good survey construction methods using item response theory and Rasch methods and things like that, you can generally avoid having a measure that's topped out. So that's one approach. Another approach is using the top box value, so you're reporting on those in terms of an experience at the best level and doing the comparison across highest level.

Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO

Gene, is there an understanding? It's just been my hypothesis that patients who return, and that's a self-selected group, I think there's one that the self-selection approved returns, and the other is the motivation and/or fear. I get worried that patients are afraid that even though everything is supposed to be, is said to be anonymous, they're afraid that their doctor will find out, and so anything less than a five, that you do with car dealerships, will hurt their care. Is there any evidence? Is this studied at all?

Eugene Nelson – Dartmouth Medical School – Prof. of Community & Family Med

Dana, what do you know about that?

Christine Bechtel – National Partnership for Women & Families – VP

Yes, this is a question too that Dana, I'm sure, can answer, but Susan Edgman-Levitan, who is a member of the workgroup, this is probably some work we could do with her offline to suss some of this out. I think it's worth doing. I'll just say while I'm talking that there are a million methodological issues with, well, frankly most quality measures, but certainly with things like experience surveys.

What I think we're looking for is an indication that there is a real and genuine conversation happening between patient and provider that includes a focus on the things that we know patients care about, many of which happen to be captured in a patient experience survey, for example. So I'm nervous about getting overly hung up around the methodologic issues when I see adaptive approaches like NCQA where they're saying, under medical home, if you're not going to do a full patient experience survey, pick a subset of these domains and just ask these questions. Folks are getting over some of the methodological heartburn around that, so I just want to encourage us to keep in mind what our end goal is and know that no instrument is really perfect for that purpose.

David Lansky – Pacific Business Group on Health – President & CEO

Christine, I'm back. Since you got the whole meeting to consider the other topics today, do you want to try to wrap up this discussion?

Christine Bechtel – National Partnership for Women & Families – VP

Well, I think we do. I think my larger question though is are there workgroup members who are able to be on the phone past this moment because it sounds like we're losing almost everybody, if not everybody. If we lose you, Dana, Paul Tang, and Gene, that leaves me, Paul Wallace, and Eva, unless we've got members who've joined that I don't know about.

David Lansky – Pacific Business Group on Health – President & CEO

Think of the power you'll have.

Christine Bechtel – National Partnership for Women & Families – VP

Yes. Paul Wallace, are you able to stay on as well?

Paul Wallace – Kaiser Permanente – Medical Director

Yes, I'm still here.

Christine Bechtel – National Partnership for Women & Families – VP

God bless you.

Eugene Nelson – Dartmouth Medical School – Prof. of Community & Family Med

Gene can stay on, but because of what you mentioned, it may be better to abbreviate it. I can stay on.

David Lansky – Pacific Business Group on Health – President & CEO

I guess I was going to make a suggestion that we had a very good discussion about all these issues, and I can see how much depth there's going to be. If people would take a couple minutes and, off line, do some markup of my memo and add, delete comments. I don't think you have to write pages, but just

flush it out a little bit of give, if there are some obvious answers, you think, to these questions, answer them. I'll consolidate all that into a second draft that might lend itself to more focused conversation.

Eugene Nelson – Dartmouth Medical School – Prof. of Community & Family Med

To get good feedback, David, I think if you frame it the way that you did for us saying imagine you were using a CAPs like patient experience survey.

David Lansky – Pacific Business Group on Health – President & CEO

Yes.

Eugene Nelson – Dartmouth Medical School – Prof. of Community & Family Med

If you put the frame in, it will help us give you useful response.

David Lansky – Pacific Business Group on Health – President & CEO

I think that's a friendly amendment to what's in my assumptions paragraph, and I think that would be, as a starting point, I think, as we get back to talking with ONC and CMS in a very practical level of 2013, that's probably the frame that's going to be most likely to be adopted. Let's use that as the starting point.

Everything else we've talked about today, we need to come back to. We probably have a little more. I guess we should do the CAPS "approach" keeping in mind these other approaches that we want to come back to, the longitudinal one with health of seniors, the panel study approach and the real time feedback, the rich feedback approach. We don't want to let them fall off the table, and I think we should try to put them in the RFI in some way.

Christine Bechtel – National Partnership for Women & Families – VP

If we either do offline work, or we schedule another conversation around these methodologic issues, I'd like to ask ONC staff to make sure that we are directly moving into Susan Edgman-Levitan, as well as Dana and Gene and others just so that we get the benefit of her long expertise on those surveys.

Josh Seidman – ONC

We will do that.

David Lansky – Pacific Business Group on Health – President & CEO

I think Josh had dialed in at some point. I don't know how much of the conversation you caught, Josh, or others from ONC. Are we going in the right direction, or do we need to be taking a different route to meet what you see as the needs on the methodology side?

Josh Seidman – ONC

No, I think this is good, and I think also that there will be more time to deal with the methodological issues, so I think that we're actually in pretty good shape in terms of the way that you've framed things in your document. I think, again, if we can get a little bit of feedback to that document, that will be helpful.

David Lansky – Pacific Business Group on Health – President & CEO

Okay. Christine, I'll ... maybe I'll just send a followup note to the whole committee saying, please give us some feedback, and I'll put in Gene's suggestion about the CAPS paradigm. Hopefully, early next week, we'll get some feedback from people.

Christine Bechtel – National Partnership for Women & Families – VP

Terrific.

David Lansky – Pacific Business Group on Health – President & CEO

Thank you, everybody.

Christine Bechtel – National Partnership for Women & Families – VP

Thank you, David. I know we lose a couple folks, and I think the next part of this is generally going to be fairly quick. I do want to check with Allen and with Josh at ONC. I think we've done well identifying the sub-domains, defining the sub-domains, and flushing out the measure concepts. We've got some potential measures as a starting point for you all to think about. But I think, generally, those four areas are in as good of shape as they're going to be in pre-RFI.

I want to check with you because what I've done is added two columns to the summary table. One is how can measures be HIT enabled or HIT sensitive. Then whether we want to flag any key questions in the RFI. My instinct, Josh and Allen, is to just focus on those two areas of HIT enablement and key RFI questions. If we take that approach, will that generally meet your needs?

Josh Seidman – ONC

Yes, I think that's very good. I think you're very close.

Christine Bechtel – National Partnership for Women & Families – VP

Terrific. Paul Tang, I'm opening up the Patient and Family Engagement Tiger Team summary table that you all had a chance to give your input on. We've got all of the changes reflected here in tracked changes. We'll leave them in unless you all have identified ones that you object to.

On the HIT enablement or HIT sensitive, if you think about self-management and patient activation, Paul Tang had said filling out surveys via PHR and possibly through survey tools that are triggered by results of like a test or a home device or reading, etc. I would at least like to add a PHR portal to that. But let me back up.

Josh Seidman – ONC

We also may want to add IVR per the comment about making it more accessible.

Christine Bechtel – National Partnership for Women & Families – VP

Good. I'm typing, so I apologize if the phone is next to it, but I'm getting our notes in here. Let me back up and remind everybody. At the top of this table, I took a stab at defining what we meant by HIT enabled and HIT sensitive. HIT enabled meaning the data collection is really facilitated by health IT, and sensitive meaning the performance measure itself is actually impacted by health IT. I think what's in the category for HIT enablement under self-management is really focused on the data collection aspect. Are there any ways that self-management and activation are, that performance on those measures is really accelerated through HIT functions and uses?

Josh Seidman – ONC

I'll just mention that one of the things that potentially could be done is because you can get data back from patients in real time, it can actually affect what goes on in the visit or in the process of developing or revising the patient care plan. So, therefore, it could actually play a much more timely role in developing a patient centered approach to care delivery.

Christine Bechtel – National Partnership for Women & Families – VP

That's a great point, Josh. In the next column over where there are key RFI questions, one of the questions that I'd like to recommend that you all explore, if folks agree, is can survey results be fed back into decision support programs so that providers, decision support in the EHR to insure that treatment recommendations and care plans, going forward, as you just said, Josh, really reflect either the patient's experience from the survey or their health or functional status, etc.

Josh Seidman – ONC

Yes.

Christine Bechtel – National Partnership for Women & Families – VP

Gene, this is really, and it may be that we want to broaden the question and also say, how else can measures in this domain or sub-domain really be embedded. How else can patient generated data really be embedded into the care...? Does that make sense?

Eugene Nelson – Dartmouth Medical School – Prof. of Community & Family Med

Yes. In terms of mechanisms, equipment embedded in care flow, the portal has been mentioned. The PHR has been mentioned. Handheld computers at the point of service or touch pads have been mentioned. Kiosks are used in many locations, computer kiosks.

Christine Bechtel – National Partnership for Women & Families – VP

Yes. That's great. I'm just adding that.

Eugene Nelson – Dartmouth Medical School – Prof. of Community & Family Med

To your point on HIT sensitive and self-management, this may be a stretch, but I think it's sometimes true that the patient is, let's say, caring for their chronic problem 24/7/365, and they might see their primary care physician for 120 minutes a year and not be hospitalized if they're lucky. One of the rationales behind patient based assessments and patient reported outcomes or health state assessment, and patient reports their level of activation, like Judith was talking about. Is that by reflecting on their current health state now, and how much it has improved or not, it's part of self-management that, in general, we learn by reflecting on what's happened, and then, based on what's happened, modifying our behaviors in the future. There's a self-reflection aspect to the self-assessment by the patient that can enable activation and learning.

Christine Bechtel – National Partnership for Women & Families – VP

That's a great point. How would I reflect that here? Is that really back to a measure concept, or is that just generally?

Eugene Nelson – Dartmouth Medical School – Prof. of Community & Family Med

I think it's to the point that by asking the patient to report on their experiences and their health does invite a reflection and reflections assist activation and self-management.

Paul Wallace – Kaiser Permanente – Medical Director

I think it's an important point that while we're creating these constructs around being HIT sensitive versus HIT enabled, there's clearly a huge amount of overlap. I think that part of the overlap is actually the ability of data to be part of a feedback loop for someone. On one hand, that's sort of HIT enabled, but the ability to impact care is the availability of the data. I think that that, to me, is a real struggle that I had with this because it also then gets to who is the clinician. I think the point has been really well made in that last example that the clinician is the patient and their family member. It's not the physician at some distant site. There's a user aspect to this too that we don't want to discount.

Christine Bechtel – National Partnership for Women & Families – VP

Yes. I think I've cataloged most of the discussion in some of the key questions for the RFI. Paul, to your point, I've included a question around how we best insure data is imbedded into the feedback loop between patients and providers. What are the tools and methods for doing that? Does that come close?

Paul Wallace – Kaiser Permanente – Medical Director

There's also the feedback loop to the patient. I think that was the point that there are capabilities and flow charts and things like that that the patient can see may be more important than changing care, weights, or BMI where the physician actually isn't even in the loop, but they may be the facilitator of access to the information through the MR in a patient portal.

Christine Bechtel – National Partnership for Women & Families – VP

It sounds like a feedback loop between the data and the patient.

Paul Wallace – Kaiser Permanente – Medical Director

Yes.

Christine Bechtel – National Partnership for Women & Families – VP

Great. For honoring patient preferences and shared decision-making, I think it's a similar list of HIT enabled, which is the data collection mechanism, so PHR. I would add mobile applications. Gene has added handheld computers or kiosks at the point of care. I'm not sure that home monitoring devices play a role in honoring patient preferences and decision-making.

Paul Wallace – Kaiser Permanente – Medical Director

I hope this isn't a digression. I think we were talking about this earlier that just the methodology gets to, there's this continuum of data we hope to get from the patient that runs from lab data to health status to preferences to satisfaction. The reality is that sometimes we actually build the capabilities by starting out with lab data, which is the segue to health status, preferences, and satisfaction. I think we have to be careful we don't discard the idea of patient monitoring devices because it's sort of like some of the devices may have both the ability to transmit blood pressure, but also health status on some scale.

Christine Bechtel – National Partnership for Women & Families – VP

Yes, I agree with that. What I have is I have home monitoring devices listed down under the sub-domain of patient health outcomes. If you think that's too limiting, let me know. Then what I'm going to suggest we do is I think the kind of questions that we have around self-management and activation are probably the same or at least apply to honoring patient preferences and decision-making, which is how can results be fed back? In other words, once you ascertain what the patient's preferences are, how do you feed that back into the care flow? I think there's an additional question, which is, that we have based on our earlier discussions, which is, are there other patient experience surveys that we ought to consider here, and how can they best be HIT enabled? Do we get some feedback we just had? Does that make sense to folks?

Eugene Nelson – Dartmouth Medical School – Prof. of Community & Family Med

Yes.

Christine Bechtel – National Partnership for Women & Families – VP

Are there other questions that we have that we want to suggest that ONC consider in the honoring patient preferences and shared decision-making dimensions?

Eugene Nelson – Dartmouth Medical School – Prof. of Community & Family Med

We received an e-mail, I think, or some materials from the foundation for informed medical decision-making, Mike Berry, about how to characterize shared decision-making, and we might want to incorporate some of what was in that material into these rows.

Christine Bechtel – National Partnership for Women & Families – VP

Yes. Do you mind forwarding that? If I received it, I don't recall it.

Eugene Nelson – Dartmouth Medical School – Prof. of Community & Family Med

Sure.

Josh Seidman – ONC

We did send it around to the group, but we can send it again.

Christine Bechtel – National Partnership for Women & Families – VP

Or just send it to me, so I don't have to dig it out, and nobody else gets another e-mail. Just making a note of that here. Great. Do we feel confident that—? I guess the question that I have here, and I think this may just be because I don't know what's Captain Obvious, but I'm not as familiar with this area, which is, how do you go about actually? Can you capture patient preferences in a structured way? If we

wanted to know, did the shared decision-making occur? Was it done well? Did it make a difference? Was it in concordance with preferences?

Maybe the only source of that information is the patient. But it also seems to me that asking the patient to consider and articulate their values and preferences around a particular condition is the critical component. Do we feel like the concepts we have here adequately capture that?

Eugene Nelson – Dartmouth Medical School – Prof. of Community & Family Med

There are, for some kinds of decisions, there are structured questionnaires that have been designed to evaluate the quality of the decision, decisional quality. So Annette O'Connor and the PHIN HIN group and others have, for certain kinds of decisions, very elegant surveys to get at decisional quality that reflects the aspects of good, shared, decision-making.

Christine Bechtel – National Partnership for Women & Families – VP

We actually do have those, so that's perfect. Great. Any other comments, questions, or thoughts on this particular sub-domain? All right. Our next is patient health outcomes. A lot of folks did some work on this section, which I think is terrific, really improved it.

I think this is an area where certainly the data collection could include through a PHR, a portal, a mobile app, a home monitoring device, a handheld computer, or a kiosk at the point of care because this is a huge range of potential measures: disease status, functional health status, risk status. I think that makes sense for that. Are there key questions that we want to explore here in the RFI, or are there other ways? Certainly this is also an area where these measures, depending on what they are, can be really HIT sensitive, meaning that the performance on the measure can be accelerated by HIT, particularly on the disease status, obviously, right. Are there other ways that these can be HIT sensitive?

Questions that folks have for the RFI here? We've actually followed up in most detail in this section that I think would be very interesting for ONC to receive some comment on and recommendations around very specific measures here as well.

Eugene Nelson – Dartmouth Medical School – Prof. of Community & Family Med

I think, right now, in one of the columns, we have children need separate measures, and we need input there. I think that might be moved to this new column that you're discussing.

Christine Bechtel – National Partnership for Women & Families – VP

Good call. Good catch.

Eugene Nelson – Dartmouth Medical School – Prof. of Community & Family Med

One of the things that has been on my mind a lot recently with respect to measuring functional health status that there are really good, widely used measures today, like the VR12 built into the health of seniors survey, the public domain version, the SF12. Yet, NIH has invested millions in new state of the art patient reported outcomes, and it's the PROMIS project, the patient reported outcome project that NIH has invested in for about eight years. There's a good a place to start. There's probably a better place to move to into the future, and so the RFI might give some thought to this transition of best current measures, stage two, 2013, best future measures, stage three, 2015.

Christine Bechtel – National Partnership for Women & Families – VP

That's what you wrote in, right?

Eugene Nelson – Dartmouth Medical School – Prof. of Community & Family Med

Yes.

Christine Bechtel – National Partnership for Women & Families – VP

Yes. I think that makes sense. Any other comments on this?

Josh Seidman – ONC

Christine, I'd like for the workgroup to provide a little bit of input into one other issue, which is the degree to which constructs, the constructs in each domain can be captured across populations versus need to be population specific. For example, patient activation or experience of care probably applies to all of virtually all of the population, whereas other measures, for example measures of decision quality or something, may need to be condition specific. It just has to do with how sort of the applicability of measures, so that might be something to discuss briefly as well.

Eugene Nelson – Dartmouth Medical School – Prof. of Community & Family Med

With respect to the patient health outcomes domain, everyone has a risk status, and everyone has a functional status. Fortunately, not everyone has a disease or injury disability status. Functional and risk are essentially universal, disease not so.

Christine Bechtel – National Partnership for Women & Families – VP

Functional and risk status are universal meaning they can be both individual and population.

Eugene Nelson – Dartmouth Medical School – Prof. of Community & Family Med

Yes, and applied to any individual, any person that has a current level of functioning, and a current level of risk, but not every person has a current disease state or disability state.

Christine Bechtel – National Partnership for Women & Families – VP

The last two areas, health activities coordination and family and caregiver engagement, I think are the areas where obviously we have zero measures, so we've got a big question in the question column, which is, how can we measure the extent to which patients are connected to community resources, right? Are there other questions under health activities coordination that we would want to recommend to ONC that they explore?

Josh Seidman – ONC

I just want to make sure I understand here. Was the concept specifically around community resources as opposed to care resources, meaning care coordination of health resources in the community as opposed to other care coordination?

Christine Bechtel – National Partnership for Women & Families – VP

I'm not sure I understand your question, Josh.

Josh Seidman – ONC

When I first saw this domain, it certainly made me think about some of the things being talked about in the Care Coordination Tiger Team. But as I relook at it, I see that there are sort of some specific things related to community resources that might be different than care.

Christine Bechtel – National Partnership for Women & Families – VP

Yes, this is specific to connection to community resources, and it may be, if folks are okay with it, that we need to rename this community resources coordination or connections to be clear about that. Anybody have an objection to that?

Josh Seidman – ONC

I think that would be helpful.

Christine Bechtel – National Partnership for Women & Families – VP

Great. So I've done that. Then we've got the last thing that we want to talk about is the family caregiver engagement, so I think that this is an area where, I think, at a minimum, we want to suggest that ONC invite some comments, globally speaking, about which measures apply, back to Josh's point, at the

individual level, at the population level, and which might be also appropriate or repurpose for caregivers when they're acting as a proxy for the patient, for example. Does that make sense?

The alternative to that would be delete this sub-domain and integrate that question in each of the above domains, which is, how should these measures be adapted for caregivers? ... sense of what to do. We held this out, so we'd make sure it wouldn't fall off our radar screen, which is right. Do we want to keep it as a separate sub-domain or integrate it through questions into the other areas?

Paul Wallace – Kaiser Permanente – Medical Director

It's kind of rows and columns question again. I tend to look at it more as a column rather than making a separate category. But that's somewhat arbitrary too, but it feels to me like it may be more efficient to look and see if there's a dimension to some of the previous where that is highly relevant as opposed to making it a whole separate category.

Christine Bechtel – National Partnership for Women & Families – VP

That's my instinct too. What do other people think?

Josh Seidman – ONC

I think it's more, it doesn't have, in a sense, a parallel construction from a construct perspective to the other things, the other domains, so I think it probably makes sense to do that.

Christine Bechtel – National Partnership for Women & Families – VP

I'm going to take a shot at articulating the question that encapsulates the two concepts that we have here, and then I can bake that question into each of the domains above. That is, is there a dimension to these measures that apply either when the caregiver is a proxy for the patient or where it is appropriate to measure the caregiver's engagement in the sub-domains? In other words, that's not maybe the best wording, but I can work on it. In other words, the caregiver's engagement in what is their health status, what are their communication preferences, things like that.

Paul Wallace – Kaiser Permanente – Medical Director

Yes, it's probably both caregiver and decision-maker.

Christine Bechtel – National Partnership for Women & Families – VP

Yes. Great. All right. I will work on that question and drop that into this and send it back to you guys at ONC. Any overall or additional questions or comments either about this table, about the process in general, etc.? You're, of course, all welcome to attend the all-day hearing. It would be great to have you, for those of you who aren't workgroup, full workgroup members, which is next week on the 28th. Any questions or comments before we go to public comment?

Eugene Nelson – Dartmouth Medical School – Prof. of Community & Family Med

You've done a great job, Christine.

Christine Bechtel – National Partnership for Women & Families – VP

Thanks. You guys have been terrific, really smart people. With that, why don't we see if we have any public comments?

Coordinator

There is no one in queue at this time.

Christine Bechtel – National Partnership for Women & Families – VP

Thanks, everybody. We will be back in touch with the next steps. We really appreciate all the time that you've put into developing this great piece of thinking that's going to inform ONC and the Policy Committee and HHS's measurement efforts more broadly. Really, again, appreciate it. We will be back

in touch with next steps. That will include David sending around the edited methodological discussion memo for your review and comments, so we'll look forward to that, and we'll talk soon.

Paul Wallace – Kaiser Permanente – Medical Director

I think he just sent it.

Christine Bechtel – National Partnership for Women & Families – VP

Great. Thank you, everybody.

Paul Wallace – Kaiser Permanente – Medical Director

Thanks.

Eugene Nelson – Dartmouth Medical School – Prof. of Community & Family Med

Thank you. Bye-bye.